THE FAMILY CAREGIVER: THE ETHICS INVOLVED IN THE TREATMENT OF ALZHEIMER'S DISEASE

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Abstract

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Alzheimer's Disease is a terminal brain disorder which causes the brain to slowly atrophy, changing many aspects of the lives of those afflicted, as well as those who care for them. Due to the unique nature of this illness that negatively impacts the personality, behavior, memory, and autonomy of the patient, many important ethical lessons can be learned during its study. This disease also presents an undue burden on the part of the millions of family caregivers who work long hours for no pay and next to no recognition from the medical field.

In this thesis, I plan to explicate the major ethical issues that surround Alzheimer's Disease, both in the case of the patient and in the case of the family caregiver. Along with ethical issues, this thesis will discuss what studies have found causes caregiver burden and potential solutions the medical field needs to utilize in order to maximize the quality of life both for the patient and the family caregiver.

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Introduction

Informed consent is a hot issue in healthcare, and has been for a long time. Informed consent has led to issues such as the right to die, or rogue doctors who wish to override their own patients' preferences when it comes to their healthcare. But not often when we consider the issue of informed consent do we discuss the informed consent of long-term caregivers. According to Carol Levine, the Director of the Families and the Health Care Project of the United Hospital Fund, there is no process currently in place for informed consent for family caregivers—either for the caregiver or even the patient himself. She says, "Health policy makers and analysts rarely consider the impact of these incentives on the 25 million unpaid, "informal" care givers in the US, who get little from the system in return for the estimated $196 billion a year in labor they provide. Family caregivers are largely invisible, as individuals and as a labor force" (Levine, 1997, pp 10). In 1997, the estimated $196 billion "industry" of informal caregivers made up 18% of the total national health care spending of 1.1 trillion dollars, which outspends both formal home health care at $32 billion, and nursing home care at $83 billion. The nearly two-hundred billion dollars spent each year in informal caregiving is not even factored into that 1.1 trillion-dollar number of our national health care spending, even though the two are inherently interwoven. Her statistics that she cited back then are now vast underestimates; today there is approximately 43.5 million of these informal caregivers in the United States (Levine, 2014). These caregivers are unpaid relatives and close friends who provide essential care and support to adults who have chronic or terminal illnesses, like Alzheimer's Disease. They are not paid a dime for their contribution to the healthcare field, but

they bear much of the burden of taking care of those they love when the system that is in place to help them ultimately fails.

Levine's story does not revolve around Alzheimer's Disease, but it still gives insight into the trials that long-term family caregivers face when taking part in the balancing act of managing a loved one's care while forming the liaison between the family member and the healthcare team. Her husband was in a car accident and suffered a major brain stem injury. He recovered, but never to 100% of the person he used to be. He was "no longer the same person in any sense," after his body had barely recovered after years, he was completely disabled, and needed 24-hour care. Nothing about this situation was fine, but from an objective healthcare standpoint everything was fine while the doctors were still informative, kind, and understanding of the tragic dilemma. But at some point during the nine years that Carol Levine took care of her husband, "[she] stopped being a wife and became a family caregiver…when he was no longer in immediate danger of dying, and as the specialists and super-specialists drifted out of the picture, [she] became invisible" (Levine, 1997, pp 13).

Many of Levine's issues stemmed from the insurance companies eventually refusing to continue payment for home care agencies. And even when they did supply revenue for her husband's care, it wasn't much. For example, at one point during her husband's disability, he needed a $3700 wheelchair that the insurance company only provided $500 for. Her secondary payer, Medicare, rejected all claims during the course of her husband's illness and rehabilitation. This struggle is all too common with family caregivers. There forms a sort of cognitive dissonance between the love one has for a family member and the acknowledgement

of the burden they factually are. In Carol Levine's words, "Love and devotion are the most powerful motives, but there are legal and financial obligations as well."

So why is it that we live in a healthcare system that often forces the family members of aged or disabled patients to take care of them with little to no healthcare training and little to no financial aid? One hypothesis is that America has always placed a high value on personal and family responsibility when it comes to healthcare. Perhaps our history of receiving spiritual or psychological rewards from the gift of caregiving has clouded the way policy makers feel about this issue. Levine argues that the problem is not simply that public policy looks first to families, but rather that it looks *only* to families and fails to support them once they accept responsibility (Levine, 2014). This sequence of events intuitively makes sense. At the outset of a family member's diagnosis of Alzheimer's Disease, one wants to be as helpful as possible. He or she will attend all checkups, and support his or her loved one as they impart on a tragic disease which has no cure. But once this family member has inserted himself into this role and the healthcare team and insurance system has recognized that fact, the role the family member has to play has been cemented into the minds of everyone involved. Once you have accepted that responsibility, it becomes an unwritten contract that binds you to the care of the patient, whether or not you receive other support.

Another hypothesis that we can form as to why the healthcare system operates in this seemingly cold way comes down to the way clinicians handle these diagnoses (Levine, 1997). Clinicians have the responsibility to give accurate explanations of disease processes and pertinent info to these eventual caregivers, but many of those caregivers have reported failures in those explanations. Caregivers who then learn a large amount of information about the

disease processes on their own and spend the most amount of time with the patients find themselves being ignored by those clinicians because they are laypeople. The issue is that these caregivers want to be educated and trained in a way that recognizes their emotional attachment to the patient. They do not want to be coddled, because they understand the gravity of their role, but they also want to be treated as a competent member of the team since, after all, they have been forced into a very central role. A diagnosis of a chronic, long-term illness which requires around the clock care such as Alzheimer's Disease is much different from a diagnosis of the flu. Such a diagnosis requires much more information and the holistic recognition of long-term implications which these caregivers need to be prepared for. Programs could be developed that train and support family care givers, but none have been created thus far at the scale needed in our country.

Chapter I – My Story

Before I explicate exactly what the moral and ethical standards our society holds both for health professionals and for family caregivers when dealing with Alzheimer's Disease, I want to discuss how this illness has affected my family. On both sides of my family, my grandfather died when I was a young age, from cancer and from a car accident. But both of my grandmothers lived a long life, and I was able to become close with both of them before they were diagnosed with Alzheimer's Disease. I want to talk about both grandmothers separately, and in length, because the amount of support they received from family caregivers was very different, and reflects the difference in care that the elderly and terminally ill received across the nation.

My grandmother on my mother's side, Grandma Gail, was diagnosed when I was in fifth grade. As I grew older and learned more, she grew weaker and lost memories. The turning point of her disease was at the beginning of high school when she called us in the middle of the night, screaming and crying about the sudden loss of her brother. In reality, her brother had died 60 years ago. It was at that moment that we knew she had to come live with us.

Once Grandma moved in, I helped my mother take care of her. I helped get her out of bed, made her tea, drove her to the senior center while she could still walk, and played piano for her. I did anything to distract her from the impending realization that she was losing every part of herself that used to make her happy. The moments that she had those revelations about her condition were the most heartbreaking. She would cry and my mother would join in. I cannot even begin to understand what it would feel like to lose my mind, even after seeing the

full progression of the disease before my very eyes. Empathy has its limits. But I could see the pain in her eyes as she struggled to remember the names of those closest to her.

Although it would be ideal for my grandmother to live with us for the rest of her life with this disease, my mother eventually reached a point in which she did not have the resources, time, or energy to continue being a full-time family caregiver. My mother has four sisters who sometimes stopped by for a few days to help out, but they all lived in different cities, some in different states. This is an issue I have personally observed in caregiving for Alzheimer's: the disease starts out as something everyone can handle. It starts with the afflicted forgetting simple obligations, or items, such as keys. It starts with funny slips in memory that everyone can laugh about, sort of like you see old people portrayed on television, as senile. But as the disease progresses, and every day turns into a new struggle, the time commitment and emotional energy the caregiver starts to spend on their loved one is an unprecedented and formidable reality. It is like taking care of a baby, but one that is full-grown, and rather than gradually learning new things and learning how to function in the world, the opposite occurs. When faced with the motivation to help your loved one at any cost, not much motivation is required to agree to take care of your loved one when he or she is in the early stages, when everything seems like a breeze. For my mother, she found out that she could no longer do this task on her own. My mother did some looking, and eventually found a senior living home, called Atria, ten minutes from our house. Atria had a separate living facility for seniors with varying levels of dementia, so we thought that it would be a good fit. Unfortunately, after seeing how Atria ran its business, and after seeing how well her mother was tended to, my mother came to the realization that staying at Atria would no longer work for Grandma Gail.

They only had a few nurses in charge of the entire dementia ward, and the ratio of caregivers to senior was too low. My mother grappled with this issue for years because she knew on the one hand that she was unable to take Grandma Gail back into her home, but she also was troubled emotionally about her mother being neglected. Fortunately, we found an Alzheimer's group home near our house, which had an opening. It was a home in Richardson which had been renovated to house eight seniors, with two round-the-clock nurses. The setting was an adequate place for Grandma Gail to spend the rest of her life; it was close enough for my mom to visit her every day, and the group was small enough for my grandmother to receive the care and support she needed in her final years.

She died my senior year of high school on my mother's birthday, December 18. By that time, she could no longer speak or walk, and death at least relieved her of the pain we knew she felt every day, though she could not tell us. It still is heartbreaking, though, that because of the lack of resources and support, Grandma Gail did not have an ideal living situation for the entire course of her disease. For my grandmother on my dad's side, though, the situation was very different.

My Grandma Bailey was diagnosed with Alzheimer's Disease in 2001, when I was only six years old, so I had a little less time to become close to her before her disease process set in, but the love she had for her family was always patent, even when her mind was gone. Grandma Bailey actually survived for much longer than my other grandma, and for much longer than the average years of survival after an Alzheimer's Diagnosis. The average life expectancy after diagnosis is around seven years, which is right around how long my Grandma Gail lived. My Grandma Bailey lived for fifteen years after her diagnosis, dying only recently on December 2,

2016. At her funeral, my dad spoke, and at one point, he said, “Since I’m a doctor, I’m in the health professions, and I see families all the time who have family members with dementia that they have to find something to do with. And I, of course, would never criticize any family for making the decisions that they made. But I’d like to point out that my mother never saw a day in a nursing home. That’s how much love this family has.” And it was true. But the reason was not simply for love; if it were, my Grandma Gail would never have seen the inside of a nursing home. It was because of vast resources. My dad grew up in a family of eight children, most of whom still live in Texas, and Grandma Bailey spent years or months living with different children of hers. Near the end of her life, she even had a full-time caregiver at the house to help out. She received the ideal, most perfect, support during her disease. I do not want to come to any irrational or irresponsible conclusions in this thesis, but it is worth noting that she lived for fifteen years after her diagnosis, double the national average for patients with Alzheimer’s Disease, and part of that could certainly be due to the high quality of care she received.

So here we have two very different scenarios: a family with few resources and a family with vast resources. Both had a grandmother with one of the most difficult diseases today, but one was forced to compromise due to lack of support. But the story of my mother’s side is nowhere near the worst that this situation can get. Many families cannot afford to have a grandparent live with them even for the short few years Grandma Gail lived with us. And certainly most families cannot afford the incredibly expensive group home with round-the-clock nurses. For most families in America, the stark difference between the amount of care and support they can provide, and the amount of care and support either one of my grandmothers

received, is saddening. That is why more effort needs to be exerted on support systems which carter subjectively to each family's abilities and needs.

Chapter II – Alzheimer's Disease: The Facts

Alzheimer's Disease is a form of dementia that is most common among older individuals, accounting for nearly 70% of all dementia patients in the world (Alzheimer's Association, 2016). The disease starts by simple short-term memory loss, then progresses to more serious memory issues such as language dysfunction, difficulty eating, inappropriate behavior, loss of the ability to self-care, and eventually the forgetting of and withdrawal from family and society in general (National Center for Biotechnology Information, 2016).

The complete and exhaustive cause of Alzheimer's Disease is not yet fully known, but there are factors that contribute significantly to the onset. One major factor in the development of the disease is genetic. Early-onset Alzheimer's Disease specifically is usually caused by a genetic mutation. This form of Alzheimer's Disease is present in patients who are between the ages of 30 and 60, and makes up only 5 percent of all people with the disease. These cases are usually caused by the inheriting of one of three genes, which cause FAD, or familial Alzheimer's Disease. Late-onset Alzheimer's Disease can also be characterized by genetics. This form of the disease involves the apolipoprotein E (APOE) gene, which has several different presentations, some of which are associated with a higher likelihood of the development of Alzheimer's Disease (Strupp, 2009). Environmental factors also play a role in Alzheimer's Disease, although these factors are less understood. Doctors recommend that even though environmental factors have a more tenuous link to the disease than genetics in our knowledge at this moment, one should continue to utilize a nutritious diet, physical activity, and healthy social engagement to help reduce the risk of any cognitive decline. As this is a

disease associated with aging, healthy habits that prevent other diseases such as heart disease are likely to be beneficial regardless.

This loss of cognitive and behavior function is caused by the gradual loss of neurons and synapses in the brain, which leads to a large amount of atrophy in any affected regions. There are many different theories as to why this neurodegeneration occurs, including one very likely reason explained by protein mis-folding, which occurs when there is an over=accumulation of folded amyloid beta protein and tau protein in the cerebral cortex (Hardy, 2002). The amyloid beta protein is a fragment the better-known amyloid precursor protein (APP), which is responsible for neural growth, survival, and repair. The accumulation of these plaques of misfolded proteins is thought to cause most of the atrophy of brain tissue seen in Alzheimer's patients. Scientists believe that the damage to the brain in Alzheimer's patients likely begins a decade or more before memory or other cognitive issues start to become noticeable, which is why methods of early detection are increasingly important so that treatments can begin as soon as possible (Hardy, 2002).

Diagnosis is completed using brain scans such as computed tomography, magnetic resonance imaging and PET scans that can help characterize the brain tissue and rule out any other differential diagnoses of other forms of dementia (Gauthier, 2014). Assessment of cognitive brain function through interviews of the patient and/or family members also can help characterize the disease and stage of Alzheimer's disease for the patient, as different individuals progress through the disease in different ways and at different speeds.

Unfortunately, there is no cure at this time for Alzheimer's Disease. Certain steps have been taken and methods have been developed to try to prevent or delay the onset of

Alzheimer's Disease, but there is no definitive evidence to support than any measure has truly been affective at preventing or delaying the progression of the disease. Seventy percent of the cause of Alzheimer's Disease at this time is thought to be genetic, but certain epidemiological studies have also pointed to diet, presence cardiovascular risk factors, pharmaceutical products, engagement in intellectual activities, and more lifestyle choices as possible factors in why certain individuals develop Alzheimer's Disease (Hardy, 2002). At this time, once the disease begins, there is no way to stop the disease as it is chronic and terminal. Life expectancy after diagnosis can be as low as three years and as much as nine years and beyond (Alzheimer's Association, 2016).

The fact that there is no current cure to the disease is paramount to the need for support and education for caregivers. We do not know how long it will be until a cure is found for this horrible disease, nor do we know if we ever will find one. Since Alzheimer's Disease is related in many ways simply to the progression of death itself in older individuals, finding a cure is like finding a cure to dying; it is much more complicated than developing a vaccine for an infection disease. In a society that gets older and older as the medical profession becomes more sophisticated, especially with the baby boom generation entering their sixties, we will have more and more patients with dementia to take care of. That's why the family caregiver is, and will become even more, important.

Chapter III—Ethical issues in Alzheimer's Disease: Early Stages

Many difficult ethical questions arise when treating a patient who has Alzheimer's Disease, and the ethical situations change and evolve constantly throughout the course of the disease process. In early-stage Alzheimer's Disease, the ethical questions typically involve answering the question as to the extent to which the caregiver and doctor should respect patient autonomy. During this stage, the patient has been diagnosed, but still maintains most autonomy over his or her own life, bodily processes, and thought patterns. The questions that must be answered during this stage is when psychiatrist should or should not refer a patient for more definitive testing, what situations genetic screening is appropriate for patients, and the overall extent to which a psychologist should inform Alzheimer's patients about the worst outcomes they should expect when creating potential advance directives (Post, 1995; Gauthier, 2013; Leblang, 1997; Howe, 2006). This stage, ethically speaking, is a critical one due to the fact that this is the last time during the patient's life before the terminal illness takes autonomy away from his or her mind and body. It is the stage during which the most important decisions going forward need to be made.

The pursuance of advanced directives during these early stages also raises ethical questions (National Institute for Biotechnology Information, 2016). Although it seems most prudent to have the patient fully and exhaustively define any actions that should be taken by caregivers and doctors after he or she loses the autonomy required to make these decisions, there is the underlying fear that having a patient go through that process is inherently harmful.

Having a patient consider each and every contingency, many of which are dismal, could be deleterious to the patient's mental health and ability to retain a positive outlook on his or her situation (Post, 1995). This fear, however present, does not overturn the immense value of this preemptive process of informed consent. The current consensus is that psychologists should encourage patients to completely consider their advance directive, preferably with the family members who will have the greatest impact on their later years present (Howe, 2006). Having those family members present is a valuable bonding opportunity that can make a patient and caregivers more at ease knowing that there is a plan for the future.

But the problems with advance directives do not end there. An advance directive for a dementia-related illness such as Alzheimer's disease is much more complicated than a regular disease process that does not involve losing complete autonomy. Many experts argue that Alzheimer's Disease does not necessarily take away one's personhood in a way that an advance directive can accurately portray the "real" person's wishes. Rather, they argue that Alzheimer's converts a patient into a completely different person, with different motivations and needs than can be predicted by a lucid patient in the early stages (Howe, 2006). Some critics take this fact and use it to argue that when patients with early Alzheimer's Disease create their advance directives, they should not be allowed to withhold life-saving measures that a later version of themselves might want. Thus, many of the questions asked in advance directives must be tailored to predict this possibility as accurately as possible (Post, 1995). A position that has been suggested is that if the patient decides to withhold life-saving measures in certain circumstances, that should only be implemented if the patient appears to have lost happiness and has begun to suffer (Howe, 2006). Common sense solutions like this need to be offered to

patients so that in their later years they are taken care of as well as possible, while holding on to the medical pillar of informed consent.

Not every expert agrees, though, that a patient who has been diagnosed with Alzheimer's Disease becomes a so completely different person during the course of the disease that he or she would be unable to accurately create an advance directive. Dr. John Paul Gaido, a graduate of UTMB's Biomedical Science program argues that before an Alzheimer's patient loses his mental capacities, the functional impairment and loss that the disease will cause can be reasonably explained and the disease's trajectory is generally predictable. In his view, because that trajectory is well known and can be elucidated to the patient, the patient has the tools at his disposal to make prudent and informed decisions regarding his treatment in the future (Gaido, 2012). This, in Gaido's words, is why a patient with Alzheimer's Disease in an early stage has both the legal authority to preemptively reject life-sustaining medical treatment, including artificial nutrition and hydration, as well as the moral authority to make such a bold rejection far in advance of the actual deed. As the ability to make such a binding and important decision is directly related to how thorough, informative, and accurate the information given to the patient is, medical professionals and licensed individuals whose job it is to inform the patient need to be especially careful to maximize the understanding of the patient and his or her family. Experts will continue to disagree on the ethics of advance directives in these complicated situations, but the existence of a medical power of attorney as an option for patients to pursue in addition to an advance directive is certainly advantageous and pragmatic.

The issue with the decision to refer a patient to more definitive testing is that a diagnosis of Alzheimer's Disease can only definitively made after death when the brain itself can be physically examined (Leblang, 1997). Because Alzheimer's Disease cannot be definitively confirmed with any test on a live human subject, there always remains the possibility for a false positive or false negative, which can both be extremely harmful, psychologically, for a patient (Howe, 2006). If a doctor accidentally tells a patient with a false positive test that he or she has a terminal illness that will take away everything that makes him or her a person who they recognize, that can be extremely distressing, and unnecessarily so. Medicine has made many strides in making Alzheimer's Disease more manageable and proceed more slowly, but not long ago there was a not insignificant risk that informing a patient of the possibility of Alzheimer's Disease could lead to a suicide attempt (Howe, 2006). This risk was so high that many psychologists believed that avoiding that risk was more important than patient autonomy. Even today the possibility of suicide is a concern for psychologists (Gauthier, 2013). However, recent studies have found that the fear of patients suffering depression after a diagnosis is more based on logic than on research, which shows the opposite (Howe, 2006). Based on these findings, informing patients of the potential for Alzheimer's Disease should be careful and tactful, but the overwhelming consensus in the field of psychology today is that yes, any patient who reports memory problems should be informed of the risk of Alzheimer's Disease, should be screened, and should likely (if the screen indicates so) undergo formal testing. This goes into the realm of informed consent; in early stages, when the patient is fully autonomous, paramount importance is placed on fully informing the patient of all possibilities so that he or she can make a prudent decision for their future care.

After the screening stage, the ethical question of how to deal with a patient who indicates that he or she does not wish to be tested or to go further down any route pertaining to their diagnosis presents itself. Current consensus is that if a patient does not wish to be screened or further tested, a psychologist should inform the patient of the risks of not being tested, but should not pressure them to change their minds (Howe, 2006). There is also the question of if psychologists should affirmatively list the option of not undergoing any testing to any given patient, or if that option should be just left open to those who specifically request that route (Post, 1995). This specific ethical dilemma is not intuitive, but is still very important. An appropriate analogy would be when the police arrest a suspect and question him before he asks for a lawyer. He does have the right to a lawyer within our legal system, but should the police have to specifically tell him that right, or is that right only afforded to those who know to ask for a lawyer? In the criminal justice system, the answer is yes, the police must affirmatively inform suspects of that right, and cannot passively use the suspect's ignorance to go about their job the way they wish to. In the medical field in regards to Alzheimer's though, the ethical solution is less clear. The moral principle of equity is better followed in a system that affirmatively gives all patients that information, and thereby that option, but some psychologists still oppose giving that extra implied encouragement to not have testing if the patient does not want it.

Genetic testing for Alzheimer's disease is also an ethical gray area (Howe, 2006; Post, 1997). Some believe that this genetic testing is similar to genetic testing for Huntington's Disease. In the case of HD, the disease has no cure as well, but in terms of patient autonomy and informed consent, the testing should be given to those who want it (Post, 1997). However,

the genotype for Alzheimer's Disease is not as accurate a predictor as Huntington's Disease is. Through genetic testing, you cannot definitively confirm that the phenotype of Alzheimer's Disease will present itself; rather, you can only predict "susceptibility," and can only determine the degree of likelihood (Qureshi, 2008). Until recently, the opinion of the psychological community was that doctors should not comply with requests for genetic testing for Alzheimer's Disease for a patient who is asymptomatic, with the explanation being that the "data are not very useful" (Howe, 2006). This approach values the supposed ethical importance of protecting a patient who likely does not have Alzheimer's Disease from a possible result that could do more harm than good in informing a patient about his or her health. The flip side is that many asymptomatic individuals who have a family history of Alzheimer's Disease may want to know, and may very well have the right to know if they have a genetic susceptibility to Alzheimer's Disease. This dilemma follows the theme that many of the ethical considerations for this disease follows: trying to balance what the patient wants or should know against the desire for a doctor or caregiver to take the action they believe is best for the patient.

Chapter IV—Ethical Issues in Alzheimer's Disease: Middle and Late Stages

During the middle stages and late stages of Alzheimer's disease, the ethics become somewhat murkier. During this time, the patient has lost much of his or her decision-making capacity, and the caregivers and doctors must attempt to balance the inherent and important respect of any amount of autonomy that the patient has left or can be afforded to him or her, along with the motivation to protect the patient with decisions that are best to his or her well-being (Post, 1995). Informed consent becomes a shaky ground because giving a patient whose dementia renders them, at times, incapable of rational thought and understanding of their situation full and candid information can be unproductive (Mcgeer, 1994). Should caregivers and doctors be allowed to withhold information or downright lie to patients in order to protect them from psychological distress? Patients with Alzheimer's Disease spend large amounts of their day in states of anxiety and distrust of others around them due to their dementia; is it wise to betray their trust simply to assuage their fears and to render them more tractable for care? I remember my own grandmother had these two dogs whom she loved, and of whom we took care after she moved into her nursing home. During the mid-to-late stages of her Alzheimer's Disease, one of the dogs died and we never told her. If we resolved to never lie to her, we would force her to relearn every single day for the rest of her life that one of her favorite companions had died. But these "lies" do not stop at stretched truths about everyday life; rather, they extend fully to all aspects of the patient's care. So we have to answer for ourselves: how acceptable is, and to what extent should we practice giving disingenuous

medical information to Alzheimer's patients when one of the most lauded and important pillars of our healthcare system is informed consent?

One practice that becomes an ethical dilemma under the microscope is "soft lying" (Howe, 2006). This is the type of lying where a caregiver gives the patient the illusion of control by presenting several options to the patient and knowing that the patient will likely choose the last choice given. The process is known as the "last-word connection." So, for example, if you ask the patient if he would rather wear the green or blue tie, he will likely choose the blue tie because it is the last option heard, and sometimes the only option remembered in the later stages of the disease. The idea seems innocent and helpful, but ethically it poses problems. Throughout the earlier stages of the disease, family caregivers have created a sort of continued trust with the patient, where the patient expects to be treated as an adult, and where the caregiver will be honest about the patient's condition. And although the patient may be cognitively impaired by memory loss, he or she may not be emotionally impaired enough to not know that the caregiver is lying. This could cause the patient to become angry and feel emotionally abandoned.

A step higher than "soft lying" is "hard lying" (Howe, 2006). This is a way to deal with the intense memory loss that occurs in the later years by simply completely lying to the patient about different issues that would give the patient anxiety if he or she were told the truth. For example, if the patient asks the same question over and over again, instead of reminding the patient of that fact, one could instead act as if the question has never been asked. Some experts even suggest that when the patient asks the commonly asked question of family members: "who are you?" the family member should lie and say, "we haven't met before, but

it's nice to meet you." Most experts do agree that in these situations, giving the patient emotional peace with lies is better than giving the patient psychological stress through cognitive truth (Howe, 2006).

Not all experts agree that lying is the answer to the potential emotional pain that the patient could suffer if given the truth. Some believe that no matter what, even in the most extreme circumstances, the caregiver should not lie to the patient (Post, 1995). The solution these experts give is to tell the truth, but in a way that is as little jarring to an Alzheimer's Disease patient as possible. For example, if the patient asks where her brother who has been dead for years is, instead of the caregiver saying, "Mom, your brother is dead," the caregiver could say, "I love Uncle Steve. I remember all the valuable things he taught me so well, that it's hard to believe he has been gone for five years. What is your favorite memory of him, Mom?" In this way, dishonesty is prevented, while psychological distress upon the revelation is minimized for the patient.

An important consideration to note when discussing lying to the patient, either through soft lying or hard lying, is the effect that it has on the caregiver's own health. The stress that caregivers take on when aiding in the treatment of Alzheimer's Disease patients is covered more extensively in a later chapter, but part of what can factor into that stress is the psychological health of the patient (Biegel, 1991). Caregivers may feel a large amount of stress when they cause their loved one emotional pain. It is easy for an expert to say that theoretically the only truly ethical option is to tell the truth at all times, but in reality, informing a patient that his or her spouse is dead every time he or she forgets—which could be multiple times a day—is traumatizing both for the patient and for the caregiver who feels responsible for being

the bearer of bad news. On the other hand, certain caregivers could be stressed by guilt when violating their integrity with their loved one by lying to them. As will be further explained, the caregiver needs to be considered as an individual and intertwined in the ethical process of this disease as the caregiver can be considered a patient as well (Haley, 1997).

In addition to informed consent, ethical questions about end-of-life measures arise when treating Alzheimer's patients who are nearing the end of their terminal disease. While it is arguable that any amount of life hold value, some question whether it is humane to attempt to keep patients alive who have reached the point where they have lost any ability to eat or take care of themselves. According to Edmund G. Howe, MD and JD, who published an article in *Psychiatry* which explicates the ethical duties of psychiatrists who diagnose and treat Alzheimer's Disease patients, a psychiatrist has an ongoing duty to the patient to assess the patient's foreseeable relative benefits and burdens (Howe, 2006). Once the patient is unable to eat without artificial nutrition, such as through a nasogastric tube, in order to maintain weight, the psychiatrist needs to consider at that point whether the benefits outweigh the burdens of keeping this person alive. But even at this point, the patient might want to live. If he or she is capable of expressing that want, that needs to be considered seriously as well. As spoken about previously, many patients do (and all should) have an advanced directive that answers many of these questions so that psychiatrists do not have to guess what the patient would have wanted (National Center for Biotechnology Information, 2016). However, many of these questions are answered by the previous version of the patient without enough empathy for what their life will really be like in that state. The medical field has to consider: can someone really imagine what it will feel like to lose your mind? The question is much like the question of life after

death. You can guess, you can have your beliefs, you may have some evidence for what will happen, but you can never really *know*.

Once again, the caregiver's feelings need to be considered in these end-of-life proceedings as well. Although sometimes advance directive will hold the answers to what life-saving measures should be taken and when, sometimes the decision goes to the caregiver (Biegel, 1991). In these instances, the mental health professionals involved need to keep the psychological health of the caregiver in mind. S.G. Post stated in a 2000 explication of Alzheimer's ethics that, "The clinician should proactively clarify for caregivers the burdens of invasive treatments to spare them the sense of guilt associated with not doing everything to prolong life" (Post, 2000). The psychiatrists should make clear that, although it may seem like the right thing to do is to exhaust every option to keep your loved one alive, sometimes with a terminal disease like Alzheimer's, you just need to let go and let the patient pass away. Taking care of a loved one with dementia is emotionally exhausting, and it is a clear fact that the caregiver is not a medical professional in these circumstances. Informed consent flows all the way from the patient to the caregiver.

Many of these ethical dilemmas in the treatment of Alzheimer's Disease do not have an immediate solution. That is why as months pass with this disease, all those involved with the treatment must continually reassess the situation (Post 2000; Howe, 2006). The psychiatrist who prescribes medication or therapy treatments must figure out what is best for the patient given all the facts he or she knows. In order to ensure the patient is taken care of, the family caregiver has that role as well. But the family caregiver is different from the doctor because the caregiver can be thought of as a potential patient as well.

Chapter V—Ethics of Care

An ethical field of study that is not as often talked about as are the tangible situations in end-of-life proceedings or advance directives are the ethics and philosophy of the relationship between a patient and his or her caregiver. Eva Kittay, a professor of philosophy at SUNY Stony Brook, describes this unequal relationship and the way the Americans with Disabilities Act legislation views provision of care by comparing it to the dependence we have on farmers (Kittay, 2011). Due to the fact that farmers do not personally feed us and that rather, we pay a middleman who pays for the farmer's goods, we then have set up an exchange between people who are independent actors in a marketplace on a level, and fair, playing field. But unlike farming, caregivers coexist with the individuals and loved ones for whom they care. The middlemen in this scenario are instead those who decide which care is provided, and if any care is provided at all. In many ways, healthcare today, especially in the United States, is treated as a capitalistic enterprise, taking place in the free market and therefore meeting perceived moral standards of "fairness." But when the caregiver, the provider of resources and life to the patient, is a family member in close, intimate proximity, and healthcare providers act as the middlemen that make decisions for what care can be provided, a relationship is set up that can be oppressive both to the patient and to the caregiver. With respect to the middlemen, Kittay states, "The person in need of care is in their power with respect to intimate details of life, aspects of existence we often do not share except with those closest to us. This is an imposition and intrusion which can be oppressive and, when it turns the disabled person into a supplicant, is experienced as being at odds with dignity" (Kittay, 2011; pp 50). We cannot ensure dignity for

those who require care to live without acknowledging the existence of an uneven power relationship that can easily turn oppressive if not watched carefully. Given that informal caregiving is not acknowledged by national healthcare spending and is not paid for through Medicaid, regulation of this care that is deeply existent in our healthcare system is practically nonexistent. The oversight needed to ensure the maximization of dignity of a patient who is supplicant to his or her provider is clearly lacking in this regard.

Kittay further explicates the harmful way the need for caregiving is interpreted in our society when she says, “the situation is worse still in a world where independence is the norm of human functioning. To the degree that the impairment requires a carer for the disabled person to live her life, care (and the carer) is stigmatized by dependency. This stigma in our society is one of many that needs to be unlearned through educative efforts and important conversations amongst friends and colleagues. Unfair stigmas, such as immovable gender roles, and stigmas against oppressed communities necessarily lead to a system of inequality that is deleterious to those communities. The disabled community, including those with dementia, too face unjust treatment due to stigmas against dependency of care. As the British Council of Organizations of Disabled People puts it, “however good passivity and the creation of dependency may be for the careers of service providers, it is bad news for disabled people and the public purse” (Kittay, 2011; pp 54). What is ironic here is that despite the dependency generally being advantageous for the pockets and career of service providers, the family caregivers involved as service providers receive none of the benefits of this unequal relationship, and instead receive much of the burden. So here we have a situation far worse and more ethically serious than a simple dependency between a disabled person and say, a

doctor in a private health system. What we have are the patient that depends on the caregiver and healthcare provider in order to live, a family caregiver that provides care but receives almost no financial aid or even recognition of work through the national healthcare budget, and a middleman—the healthcare industry—that benefits through profits, dependency, and free labor from the caregiver.

Another issue in the ethics of care that needs to be examined is the view of "selfhood" in patients with advanced dementia (Held, 2007; Dewing, 2002). As described earlier, some experts believe the "self" is changed during the course of the disease, leading to the development of a new person with potentially different motivations than before. But Pia C. Kontos, a senior scientist at the Toronto Rehabilitation Institute and associate professor of public health at the University of Toronto, states that premises like these that come to define dementia care practices "denies the body an agential role in the constitution and manifestation of selfhood" (Kontos, 2005; pp 553). She argues that, "Dementia care practices must embrace the idea that the body is a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge" (Kontos, 2005; pp 554). In her view, in order to satisfy the requirements for the achievement of person-centered care, the body itself cannot be excluded. The idea that the deterioration of the mind leads to a completely different person can hinder care in ways that are easily conjectured (Dewing, 2002). For example, the perceived loss of selfhood in a patient with advanced dementia could lead to lower-quality care than would be provided for someone with a "fully-functioning" self. Denial of adequate care to those who cannot express a need for that care is unacceptable when the reason for that denial finds its roots in an immoral stigma rather than objective truth of the patient's condition. The way

healthcare providers and family caregivers perceive dependence and let that perception inform the way they treat patients can lead to what Kitwood described in his studies in the 1990s as "malignant social psychology." Treatments that involve practices such as infantilizing, stigmatization, intimidation, and objectification can damage patients' already fragile self-esteem, which can lead to a loss of selfhood" (Kontos, 2005). Although some of the loss of selfhood can arguably be traced to the neuropathology of dementia, much of that loss of selfhood is also attributable to unfair treatments that embrace the stigma of cognitive decline equaling the decline of selfhood. Insofar as a person's selfhood is perceived as directly related to mental agency, Kitwood argued that "as the ability to manifest agency clearly becomes impaired due to increased neuropathology, selfhood needs to be sustained increasingly by the facilitation of others. Where care providers fail to attend to the subjectivity of those with dementia, or 'unintended dementia,' the inevitable result will be 'a dismantling of personality, a loss of self'" (Kontos, 2005; pp 555). This point of view brings back into the spotlight the importance of treating all patients with dementia as individuals with unique needs and motivations—aspects that make a patient a person above all else. Because the loss of mind and agency is at the forefront of this disease's pathology, treatment cannot be in a cookie-cutter fashion. Doing so increases the risk of, or hastens the arrival of, loss of selfhood. Ethically, that loss needs to be prevented or minimized through interactions that stress the importance of the individual.

Much of this idea of the "ethics of care" is nuanced, and the philosophy does not always translate well to concrete, tangible changes that can be made as a response to these lapses. But the argument explicated above does not seek new medications or specific treatment options;

rather, it can act as a call for empathy and understanding by the healthcare field and the providers who may take individual agency for granted when caring for someone with advanced cognitive decline. When drafting healthcare legislation, or simply putting treatment duties into action on a daily basis with an Alzheimer's patient, decisions on how to treat a patient with dementia need to be informed by the stigmas our society have created against natural dependence, as well as the immediate risk of the loss of selfhood on the part of patients with dementia.

Chapter VI—The Burden of the Family Caregiver

There also exists the burden that the caregiver him or herself shoulders when taking care of their loved one. A study in 1987 by the University of Washington Medical Center found that the amount of vulnerability and resources that a given caregiver possesses are good predictors for the amount of distress he or she will face (Kiecolt,-Glaser, 1997). Much of the rhetoric surrounding Alzheimer's Disease is patient-centered, but neglects the fact that caregivers under a large amount of stress are at times in need of interventions as well. The University of Washington study suggested that after developing a system to screen and identify at-risk caregivers, there be specific interventions, such as stress management or skills training, in addition to increased resources through provision of support services in order to reduce caregiver burden. As a result of the finding that certain combinations of stressors, vulnerability of the caregiver, and resources are more harmful to mental health than others, fixing this problem will require specifically tailored interventions. Although numerous caregiver intervention programs exist (Donaldson, 1998), there still is a need for more individualized programs that can target specific needs and coping strategies, as each caregiver has a different degree of stress, and each caregiver develops and benefits from unique methods of coping.

The fact that Alzheimer's Disease has been linked genetically and that high levels of stress can exacerbate and progress the onset of the disease should give anyone pause when considering that many caregivers of patients with Alzheimer's disease are their children or other blood relatives. Both types of Alzheimer's Disease: early-onset and late-onset, have certain genetic components involved in their genesis (National institute on Aging). Although not

all risk factors for the development are known, and the degree to which each factor contributes is not completely understood at this point, this genetic component makes it more likely for a family member, a potential caregiver for the original patient, to develop Alzheimer's Disease later in life. Given that these family caregivers can be seen as potential future victims to this disease process, we should be mindful of those other, lesser understood, risk factors by taking care of the caregivers as well.

According to the Alzheimer's Association, there are ten common symptoms of caregiver stress which should be monitored by all involved in the caregiving. This includes denial about the disease and its effect on the patient, anger at the patient or the situation, social withdrawal, anxiety about the future, depression, exhaustion from taking care of the patient, sleeplessness, irritability, difficulty concentrating, and general health problems that are exacerbated by stress (Alzheimer's Association, 2016).

A study in 1999 showed a hypothesis that chronic stress is able to accelerate the appearance of Alzheimer's Disease and is a risk factor for the disease (Schneider, 1999). A study as far back as 1987 showed that family caregivers with Alzheimer's Disease victims at a higher level of impairment (thus with more work for the caregiver to do) had higher amounts of distress and loneliness (Kiecolt-Glaser, 1987). When this study compared these caregivers with control subjects, the researchers found that caregivers had significantly lower levels of T lymphocytes and helper T lymphocytes than comparison subjects. In simple terms, the researchers found that caregivers with high stress patients to take care of did not have the immunological or psychological adaptations that other control subjects had at their age. The disease was not only harming the patients' minds, but also was harming the caregivers' health.

At the surface, it appears this discovery could be useful. We could put out Public Service Announcements to inform citizens to lower their stress levels to try to decelerate any appearance of Alzheimer's Disease. But it is not that simple. Most everyone knows that stress is unhealthy; it is a risk factor not just for Alzheimer's Disease, but for a host of other illnesses. The problem that needs to be fixed is the one causing the stress. We have an entire population of family members already with a large genetic risk factor for Alzheimer's disease who are put in an immensely stressful situation for whom we have not developed enough resources. The situation of becoming a caregiver of a loved one with Alzheimer's Disease is one that takes over your life, swallowing other fulfilling activities, and requiring emotional and economical labor that at present causes much more stress than should be taken by a person. By letting the system fail these caregivers, it not only is deleterious to the patients themselves, but also to this population of people who we are giving all the risk factors they need to develop Alzheimer's later in their lives.

Chapter VII—Caregiver Burden: Causes and Solutions

Different coping strategies for caregivers have been developed over the past few decades for dealing with Alzheimer's Disease: both by the caregivers themselves and the professionals who look at general stress models. Psychologist Sally Wai-Chi Chan noted in her research article on the global problem of family caregiving for dementia that caregiving is "an acute reaction to providing care that arises as new care demands are introduced or existing care demands intensify. When care demands become increasingly challenging, caregivers respond by employing strategies to meet care demands and decrease the burden of providing care" (Chan, 2010; pp 471). Those family caregivers who are not able to tailor their strategies to meet the demands of caregiving quickly and who cannot easily mitigate the stress patients put on them are more likely to suffer distress as a result.

As the progression of Alzheimer's Disease is complex, the strategies caregivers can use to cope are numerous, and many researchers disagree on which strategy is best. A study in 2007 found that a problem-solving approach to alleviating the demands of patients is more advantageous than an emotion-centered approach (Schubart, 2014). However, an earlier study in 1996 posited that the two approaches could not be separated, and that the emotions that surround the problem solving make the two strategies inherently commensurate (Akkerman, 1996). But the binary of which approach is followed, or if both can simultaneously be followed, are not the only factors which affect caregiver burden.

For instance, the degree to which the family collaborates and rallies to take on the challenge of having a loved one with Alzheimer's Disease makes all the difference. If the family

relations are supportive and collaborative, where everyone does his or her best to pitch in, the caregiver burden can be reduced. On the other hand, if the caregiver feels isolated and as if he or she is shouldering the immense burden alone, caregiver distress is exacerbated. The anecdote of my personal experience is enlightening in this regard. My father's side of the family had eight children who kept up constant communication about the care of my grandmother, who each took my grandmother into their homes, and contributed to the amount that each child's personal situation allowed. My mother's side of the family had a main caregiver—my mother—and then four sisters out-of-city or out-of-state, whose maximum role at any time was that of a babysitter for my grandmother. This is not a critique of my mother's family though; rather, it is a reminder that every family's situation is different and must be viewed as such by the medical field. Families like my mother's and families with even lesser of an ability to take on the caregiver role need more tangible support than others do.

Just as different family caregivers find themselves in varying levels of support from other family members, many caregivers follow different models in coping with the burdens of taking care of patients with dementia. The psychological community on this issue has emphasized an individualistic approach to coping rather than a homogenous approach (Gubrium, 1988). It seems obvious that each individual reacts differently emotionally to the complex struggle that characterizes caregiving of this sort, but the point is important when considering how best to support these caregivers. A cookie-cutter, objective approach clearly is not the answer. In 2010, psychologist Sally Wai-Chi Chan identified a few different models that caregivers use to cope. One such model is the "biomedical model," in which caregivers understand to a fundamental level that Alzheimer's Disease is a brain-based process and is

completely abnormal. They willingly accept those facts of the disease and tailor their caregiving and coping to that very understanding. A different approach is called the “folk model,” in which the caregiver simply views Alzheimer’s Disease as a natural aging process and bases their care and coping on the euphemistic qualities of that viewpoint. A third model, the “mixed model,” is a combination of both aforementioned models, in which the caregiver utilizes and understands those biomedical facts of the process, but approaches the actual origins of Alzheimer’s Disease with the naturalistic ideas of the folk model. Most caregivers likely fall somewhere on the spectrum between the two extremes of biomedical and folk models of caregiving and coping. For, it is unlikely that any caregivers partial to the folk model unequivocally believe that Alzheimer’s Disease is simply a normal product of aging. But psychologically, the two main models are sensible reactions to the disease for scores of different individuals. Fact-driven, science-enthused individuals may be more likely to need to know the exact disease processes: why this is happening to their family member, and how, biologically, that takes place. How to slow the process, what clinical trials are available, what scientific discoveries have been made or may be made in the near future. Their minds just work that way. Others may understand many of these facts, but also have an understanding within themselves that dealing with this tragedy needs to involve maximizing the time they have with their loved ones in an environment as normal to watching a loved one age as possible. The main point that we can glean from these models is that an individualistic approach needs to be made when educating potential caregivers on coping. The conversation needs to be had: is your coping driven by knowing all of the biological facts, or do you want to make the process seem as natural as possible? Of course, the patient’s needs need to be kept in mind as well, but the caregiver’s

stress levels and well-being depend on tailoring a treatment approach that maximizes the comfort of everyone involved. The conceptualization that a caregiver has of their loved one's dementia holds a high amount of causation upon how that caregiver will solve relevant problems, the degree to which the caregiver perceives his or her burden, as well as how likely the caregiver is to recognize their burden and to seek help in turn (Gilbert, 2011).

Demographic and Personal Risk Factors for Caregiver Burden

Certain demographic information and personal history can help to predict the magnitude of burden a caregiver will face. A 2004 study found that being a spouse was associated with a higher level of perceived burden (Mohamed, 2004). In addition, the caregiver's demographic information, such as their age, income, gender, and employment status are correlated with experience of burden. In 2010, the World Federation of Mental Health concluded that middle-aged and older women who act as a caregiver for a family member are six times more likely to experience symptoms of depression than the national average (Mohamed, 2010). It is also true that women are more likely to become family caregivers due to the fact that the traditional role of caregiving is often both expected of and performed by women. (Lai, 2012). Level of income also comes into play when discussing risk factors for burden, as it has been found that lower levels of income are associated with a higher risk of caregiver burden (Mohamed, 2004). This risk factor is intuitive, as one with a lower income would have less resources available to care for the patient. He or she may not be able to afford to put their loved one in a nursing home, or a group home, and may not be able to hire a part-time non-familial caregiver to take some of the strain off. In my personal case, both of my grandmothers were taken care of full-time by non-familial caregivers in their final years of life, which certainly reduced the burden on my parents and relatives.

Another factor that affects the magnitude of burden a caregiver will face is their specific familial relationship with the patient. The two most common relationships between caregiver and patient are the adult-child relationship—where the caregiver is the patient's child— and the spousal relationship. A 2014 study on the impact of Alzheimer's Disease caregiving found

that the caregivers in the adult-child relationship had a greater burden than those in the spousal relationship, despite spending less time on all aspects of caregiving (Reed, 2014). One hypothesis that the study suggested could account for this inconsistency is that the spouse is generally the same age as the patient who is battling dementia. Many of the changes the patient has been through in terms of aging naturally has been shared by the spouse. In a way, the spouse has already adjusted to an elderly way of living, which makes caring for an elderly person less jarring and stressful than a child of the patient who may not be ready for a sudden change in lifestyle. The study concluded that although they found that adult-child relationships carry a heavier burden and some other studies found the opposite, the two types of relationships clearly have different needs. In fact, that same study found that irrespective of the specific caregiver-patient relationship, patient functioning and caregiver distress through patient behavior were both associated with caregiver burden. Therefore, although this demographic and personal information can give us interesting insights into which groups are affected most by this indirect cause of stress, we have to focus most on the causes of burden that we can change, and inevitable amounts of burden that we can try to stop.

Specific Caregiver Hardships

Up until this point in this thesis, many of the challenges that face caregivers of patients with dementia have been vague and applicable to anyone emotionally coping with a family member in poor health. But specifically, hardships of caregivers for patients with Alzheimer's Disease and other similar forms of dementia have been studied, and include personal problems, social issues, and debilitating health.

Duration of illness is a specific challenge that these caregivers face. According to the Alzheimer's Association, the average life expectancy for a patient who has just been diagnosed with Alzheimer's Disease is eight years, while some patients can even live for 20 years after diagnosis. Caregiving of this sort is different from taking care of a child who is sick and home from school. This caregiving involves around-the-clock care, the bathing of a full-grown adult, sometimes (and all the time) feeding the patient each meal, helping move the patient when he or she no longer has that independence, and more. It involves arranging doctor's visits, taking time off work to go to those doctor's visits, not to mention any other obligations one has other than simply caring for this family member. Having this duty over an average of eight years—and sometimes much longer—is especially taxing, and the sheer time commitment contributes to the burden these caregivers face.

Another factor that contributes to caregiver burden is that this burden can cause clinical depression both during the patient's battle with the disease and after he or she has passed. Witnessing a loved one deteriorate both mentally and physically for a long, drawn-out period of time certainly can cause grief and depression for the caregiver who spends these years in close contact with the patient. Chronic depression after the patient's death is also common, both

caused by the pre-existing grief during the disease process, and the grief that occurs as a result of the death itself (Aneshensel, 2004). A study in 2003 showed that 40-50% of family caregiver who took care of patients with Alzheimer's Disease or similar forms of dementia had clinically significant levels of depression at the end of the patients' lives (Shultz 2003). The psychiatric symptoms that caregivers face as a result of their situation is also associated with an increased likelihood of patient nursing home placement (Mohamed, 2014). This is because symptoms such as depression increase the burden that caregivers feel, which in turn increases the impatience caregivers have with the patient, leading them to be more likely to underestimate the patient's independence and functional capacity. This avalanche of causal events makes it more likely for a patient to be placed in a nursing home or other skilled facility before the time comes that this step is necessary. So the psychological burden a caregiver faces not only affects the caregiver's health and well-being, but also those of the patient.

Although caregiver depression is common when coping with the care of patients with dementia, some studies have suggested that caregiver burden could be related more to social dysfunction and behavioral disturbances than to cognitive deficits (Mohamed, 2004). 'Behavioral disturbances' refers to the behavior of the patient while under the care of the caregiver. In fact, neuropsychiatric disturbances, such as aggression and paranoia, increases the likelihood of nursing home placement more so than does objective declines in cognitive abilities on behalf of the patient. As the dementia takes hold of a patient and takes his or her mind away, the patient transforms into a different person with different behaviors, many of which are insubordinate or cantankerous. During the course of Alzheimer's Disease, 67% of all patients, or two-thirds, develop a 'psychotic' symptom, which can causes hallucinations,

delirium, and a host of inappropriate behaviors. (Gaido, 2012). Greater than 50% of all Alzheimer's patients demonstrate aggressive behavior, and almost 20% of all Alzheimer's patients assault their caregivers at least once during their care. Other behaviors that are commonly known to give distress to families of patients include "nighttime awakening and wandering, suspiciousness, accusatory behavior, incontinence, and violence" (Gaido, 2012; pp 112). This causes a need for constant supervision, which is stressful for family caregivers. Orbell argued in 1996 that, "the burden of caring for a person with dementia depends on the extent of disruptive problems such as aggressive behaviors, incontinence, and wandering (Orbell, 1996). In fact, many articles on this subject support the notion that caregiver burden will increase as the severity of symptoms increase (Vetter, 1999; Pruchno & Resch, 1989). One study in particular, by Justine Schneider in 1999, found that the type of behavioral disturbance is telling in its impact on caregiver burden. She found that the majority of behavioral impact on burden was due to behavioral deficits, such as stubbornness, apathy, and lack of cooperation, rather than behavioral excesses, such as aggression, mood swings, and restlessness (Schneider, 1999). As there are many factors in play with caregiver burden, behavioral disturbances accounted for 5.7% of the variance in burden, which made it the most striking finding in the study. At 1.6% of the variance fell a weaker, but still statistically significant factor of any element of the patient's cognitive impairment such as memory problems or language loss. It is significant that the daily stressors of behavioral issues are so much more related to burden than the long-term stressors of the patient's memory loss. Cognitive impairment does not have a cure at this point, but behavioral issues can be fixed in the short term, either through the use of medication as discussed later, or through prudent, logistical changes to the patient or caregiver's schedule.

Economically, caregivers faced hardships as well. In a cross-national study of co-residential spouse caregivers for people with Alzheimer's Disease, 61% of sample participants reported having additional expenses due to their role as caregiver, but only 31% reported receiving additional financial help. More than 10% of participants reported feeling 'very dissatisfied' with their financial position. Although these data are based on perception of economic toil, the variable of perceived economic hardship held a statistically significant association with the overall caregiver burden score (Schneider, 1999). According to the Alzheimer's Association, the median cost of a home care aide is $20 per hour, and the average cost of a semi-private room in a typical nursing home is $80,300 a year (Alzheimer's Association). So even if a family caregiver has hired help to reduce the psychological burden of taking care of a patient as a family caregiver—not a healthcare provider—the financial burden involved is still significant. Also from the Alzheimer's Association, approximately two of five unpaid family caregivers in the United States have a household income lower than $50,000 (Alzheimer's Association). For some families, the ends do not meet in a way that allows them to both spend the money and effort to take full care of their loved one while simultaneously keeping in line with their other financial obligations. In a Family Impact of Alzheimer's Survey based on 3,500 interviews in late 2015, 500 respondents reported providing caregiving or financial aid of some form to a person with dementia. Of those 500, 93% were family members, and the financial aid given, on average, amounted to more than $5,000 per year for supplies such as food, travel and medical supplies, and diapers. An important point to note form this survey was that nearly half of those caregivers reported cutting back on spending for themselves. This cutting back includes 20% of respondents going to the doctor less often, 11%

not filling all of their prescribed medications, and 11% cutting back on their own children's medical expenses, all to channel financial resources into a patient with dementia (Alzheimer's Association, March 2016). Not only are family caregivers giving their own money to help loved ones with dementia get the simple supplies they need, but they are also taking money away from important aspects of their lives such as their own health and the future of their children.

This financial stress clearly puts an undue burden on family caregivers. A separate economic study based on a sample of 240 caregivers in 2012 found a significant association between financial hardship and caregiver burden (Lai, 2012). The financial hardship is characterized not just by the basic, daily level of economic sacrifices a caregiver must make to care for the patient, but also to the caregiver's personal finances. Caregiving can lead to a loss of productivity of the caregiver in his or her daytime job, as well as a general loss of income due to the loss of potential career advancements due to the time constraints of caring for a patient with Alzheimer's Disease. Compared to coworkers who do not have a second, unofficial job as a caregiver, family caregivers have to take more time off work for various appointments, are interrupted at work more often, and ultimately work fewer hours than desired Other miscellaneous caregiving financial costs include transportation, nonprescription and prescription medications, and medical supplies. The kicker: the costs of caregiving are not usually covered by private insurance programs (Arno, Levine, & Memmott, 1999).

The four other variables in the Schneider study that held a strong association with burden were country, younger ages of caregivers, patient behavioral issues, and perception of a negative social reaction. The last factor refers to the perception of the caregiver as to social

withdrawal and the ability to have a social life as a caregiver. Since caregiving is a full-time job, social withdrawal is a common reality, and contributes to the ultimate burden a caregiver faces.

Despite how complicated different factors play a role in burden, two of the most difficult challenges faced by those who take on this role as a caregiver can be summed up in two words: loss and entrapment (Schneider, 1999). They experience two losses of their loved one: both the loss of their mind, and the loss of their body. And both losses are drawn out significantly. Due to the fact that the average life expectancy after diagnosis is eight years, they are entrapped in their roles as caregivers once they agree to take it, and they experience this gradual loss at very close quarters.

Measurement of Caregiver Burden

In 1998, a scale was created to measure the impact of neuropsychiatric symptoms in patients with Alzheimer's Disease on the overall burden of the caregiver. This scale was based on the original NPI (Neuropsychiatric Inventory) and is called the NPI-D. The NPI-D was confirmed to be a reliable scale based on its comparison with the pre-existing Relatives' Stress Scale, which measures caregiver stress generally, but not in a way that specifically assesses caregiver burden in Alzheimer's Disease and related dementias like the NPI-D does. The 1998 study that created this scale also concluded that the neuropsychiatric vacillations that characterize Alzheimer's disease patients are more strongly causal in the development of caregiver distress than cognitive deficits are (Kaufer, 1998).

Another method used to measure caregiver burden, which is now the most commonly used instrument for such purpose, is known as the Zarit Burden Interview (ZBI). The ZBI is a 22-item patient assessment, which includes semi-structured inquiry into the patient's history of cognitive symptoms and behavioral performance. The ZBI tool is both quick and efficient, usually administered to patients in less than five minutes (Stagg, 2010). The significance of such brevity is that it can easily be implemented into clinical rotations without much effort or the need to restructure clinical events to account for the test. Since caregivers are generally present for appointments that the patient has, it would not be difficult for the physician to add in the ZBI test periodically in order to gauge how the caregiver is coping with his or her new and taxing responsibilities.

Potential Solutions to Caregiver Burden

As the burden that a caregiver experiences has been studied enough to conclude that the burden can be deleterious to the caregiver's health, methods for mitigating that burden have been studied as well, although more research is needed in this subject. These remedies can either target the caregiver himself, or the patient who—through no fault of his or her own—causes much of the burden.

One way to reduce caregiver distress is to try to improve the behavior of the patient. Behavioral problems are extremely common in Alzheimer's patients. Agitated or aggressive behaviors occur in 70% of patients, while certain delusions and hallucinations occur in 30-50% of patients (Mohamed, 2004). As stated earlier, studies have suggested that caregiver burden may more so be a consequence of behavioral disturbances than cognitive deficits in the patient (Kaufer, 1998; Mohamed, 2004). Simply put, the magnitude of the burden may come more from the stressful atmosphere of dealing with a patient whose dementia causes aggressive or confusing behaviors than from the fact that the patient's memory is evaporating. This causal relationship between bad behavior and burden can be reduced by pharmacotherapy with certain antipsychotics (Mohamed, 2014). The results of Mohamed's 2004 study showed that in patients that display relief of these behavioral symptoms, caregiver burden was also likely to show relief. Specifically, the antipsychotic medications olanzapine and risperidone—which are part of a class of antipsychotic drugs known as "atypical antipsychotics" and help to restore balance to natural substances in the brain (Mcgeer, 1994)—were particularly found to have beneficial effects on the patients' NPI (Neuropsychiatric Inventory) total score, which is a measure of psychiatric and behavioral symptoms. Since the NPI was found to be the most

reliable predictor of perceived burden of caregivers, plus changes in NPI score was strongly correlated with changes in burden levels (Mohamed, 2004), interventions which target the patient's behavior would necessarily also target the caregiver's burden. Of course, it seems intuitive that the patient's erratic behavior would be treated regardless, but when making decisions on what behaviors are acceptable, and how aggressively neuropsychiatric disorders in the patient should be treated, the effect on the caregiver should be taken into consideration. One issue with the medication path, however, is that antipsychotic medications such as the ones listed above were not found to be beneficial in improving the patient's quality of life (Sutzer et al, 2008), which is a factor of profound importance to many family caregivers (Karlawish, 2000). In this 2000 study, researchers found that improving the patient's overall quality of life, such as by ensuring the patient interacts socially, continues pre-diagnosis hobbies, and maximizes happiness, also has a large impact on caregiver burden. All of these findings trace back to the fact that the amount of stress or burden a caregiver perceives is directly related to how well the patient is doing. Although Alzheimer's Disease is terminal, and debilitation of the patient's autonomy, memory, and behavior cannot at present be stopped, these insights prove that care that maximizes the well-being of the patient can help to minimize caregiver burden in the long-run. The emphasis of this point is again, not necessarily the obvious conclusion, but the charge that the well-being of caregivers needs to be a significant part of the conversation when making important treatment decisions on the patient's behalf.

Practical methods for mitigating burden involve more than just treating the patient better and thus instituting a "trickle-down" system of burden relief. The 1999 study by Schneider laid out a few practical considerations, in addition to fixing the behavior of patients.

In addition to clinical issues, public attitudes and education could help a caregiver feel less socially isolated, economic support could help caregivers feel less financial stress, and certain groups of people more vulnerable to these burdens (such as young women), could be targeted for participation in support groups (Schneider, 1999).

The economic support called for by multiple psychiatrists in the field (Mohamed, 2004; Schneider, 1999; Lai, 2012) needs to come from and be recognized by both medical providers and insurance agencies. The fact that most private insurance companies do not recognize informal caregiving despite it being 18% of the total national healthcare spending in the United States is unbelievable. It is impossible for a family to prepare to take care of a patient with dementia when they know how exorbitant the costs are going to be, but their insurance provider and physicians cannot guarantee that the care will be affordable. As the baby boomer generation reaches the age range in which Alzheimer's Disease is rampant—which is mere decades away—the total cost of informal care in the United States will keep increasing. Now more than ever, we need to prepare for the economic reality that an increased overall life expectancy gives us. Although more people live longer, they now can live long enough to develop diseases that are characterized by old age, such as Alzheimer's Disease.

As recently as July of 2016, an Alzheimer's Association advocate named Connie Bastek-Karasow, who is a caregiver for her Alzheimer's-afflicted husband, urged Congress to work to improve the Medicare system to provide better care both for the patients and the family caregivers who face financial burden in making up for the lapses in care the patient can actually receive from Medicare. The Alzheimer's Association in recent years have attempted for reasons such as these to lobby Congress to pass the HOPE (Health Outcomes, Planning and Education)

for Alzheimer's Act on the heels of the CMS Proposal to Improve Access to Care Planning Services. This act was one of the Alzheimer's Association top priorities for the 114th Congress, and ended up successfully passing. New services based on HOPE would allow patients diagnosed with Alzheimer's disease to receive comprehensive care planning services, which would include conversations for the patient and family caregivers to be a part of that would be imperative to be prepared for the disease as it progresses (Alzheimer's Association, 2016). The HOPE for Alzheimer's Act also increases the access to information on the care and support for individuals who have been newly diagnosed, along with support for families. Its purpose was also to ensure that the Alzheimer's or dementia diagnosis would be documented in a patient's medical record, in order to aid in the coordination of care and the management of any other conditions. The act also ensures care planning services by requiring the Secretary of Health and Human Services to conduct provider outreach that would provide professionals of the new benefits of HOPE as well as requiring Human and Health Services to report both to the Advisory Council on Alzheimer's Research, Care and Services as well as to Congress whenever there are barriers that any beneficiaries of HOPE face in receiving the new services. These types of bills need to continue to be lobbied and brought to Congress in order to provide the support and care planning logistics that all patients and their family caregivers need to have access to.

The fact that most of the caregivers for these patients are women needs to also be considered when discussing ways to fix this system. Women have been found to not only be overrepresented as caregivers, but also spend more time with the patients than male caregivers do, receive less assistance with tasks than their male counterparts, and have to balance caregiving with more domestic chores than male caregivers do (Lai, 2010). Female

caregivers need to have more gender-tailored support from medical service providers than they do at present. Care providers must consider gender-specific challenges that may exacerbate the stresses of caregiving, such as if a mother is both taking care of her parent with Alzheimer's disease and raising her children at the same time.

Conclusion

As our population continues to age and modern advances continue to slowly increase our life expectancy in the Western world, diseases characterized by advanced age like dementia will become more of a problem. Given that we know that we are far from a cure and that we know that millions of Americans will continue to develop this disease over the coming decades, we need to be prepared: both from a practical standpoint, and an ethical one.

Practically speaking, we need to be vigilant when it comes to caregiver burden. Since it is well known that extreme stress—caused in this case by behavioral deficits, aggressive actions, cognitive deficits and severe dependence on the part of the patient—is unhealthy for the human body. Knowing that Alzheimer's Disease is a genetically linked form of dementia, knowing that many caregivers are blood relatives, and knowing that studies have shown stress to be a risk factor in the development of Alzheimer's Disease, there is a very clear mandate that needs to be followed: family caregivers face unreasonable amounts of stress in today's healthcare world, and that stress needs to be mitigated as much as possible. In this regard, there are several paths to follow that are not mutually exclusive. For one, we need to figure out the best way to treat dementia patients' behavioral deficits as much as possible without further harm to the patient. If pharmacology cannot provide a solution to behavioral deficits that is not detrimental to the patient, we need to find another way to treat behavioral disorders, whether it be therapy or another route. Additionally, knowing that middle aged women are both the largest represented demographic in family caregivers *and* suffer a higher amount of burden than other demographics means that much of the caregiver burden we see in our country

amounts to a women's issue that needs to be recognized as such. Practically, all family caregivers need to be considered potential patients in this process, and full informed consent needs to be obtained, whether "legally" or otherwise, since many caregivers suffer their own health problems partly as a result of the task they put on themselves, or in some cases the task that is put on them. And practically, informal healthcare needs to be recognized in the figures for national healthcare spending, and the economic burden on families dealing with Alzheimer's Disease needs to be improved. When a family caretaker is performing the job of a full-time nurse and spending money out of pocket for essential medical supplies on top of other obligations such as working to provide for the family and raising children, that is a broken healthcare system. Our healthcare system should practically care for the most vulnerable, and advanced dementia patients and their struggling family caregivers certainly falls into that category.

Ethically, we also need to be prepared to deal with dementia as the number of Americans embroiled in the disease process, either as a patient or a caregiver, increases. Much of the most important ethical considerations for Alzheimer's Disease, such as ethical standards for the providing of additional testing, or genetic screening, has been well explicated by experts in the field of medical ethics. Ethical considerations of the efficacy of advance directives and the decisions we make in end-of-life procedures continue to be heavily debated on both sides. The ethics of care that the healthcare field needs to take into consideration is just budding, but all healthcare providers need to strongly consider and enact into protocols what ways to minimize negative perceptions of dependence and the oppressive systems that can emerge from those perceptions. Most importantly, when considering the ethics of treating a patient with

Alzheimer's Disease, the discussion needs to spill over into the ethics of "treating" the family caregiver. There are extensive studies that have concluded the link between the deficits involved in Alzheimer's Disease and the burden felt by family caregivers. Our awareness of that unfortunate impact gives us in the healthcare field an ethical duty to treat the pitfalls of informal caregiving as we would treat any other healthcare crisis: we need to recognize it, and we need to form a plan to fix it.

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Biography

Daniel Bailey was born in Dallas, Texas. After graduating from JJ Pearce High School in 2013, he attending the University of Texas at Austin and joined the Plan II Honors program and the Chemistry Department as a student. In college, he was the captain and president of the Texas Mock Trial team and conducted research in biomedical brain imaging. He graduated in 2017 with a B.A. in Plan II Honors and a B.S. in Chemistry. This summer, he will begin medical school at Baylor College of Medicine in Houston, Texas.